

DOCUMENT RESUME

ED 232 382

EC 152 680

AUTHOR Hanson, Janice L.
TITLE Impact of the Diagnostic Process on Parents.
PUB DATE Apr 83
NOTE 21p.; Paper presented at the Annual International Convention of The Council for Exceptional Children (61st, Detroit, MI, April 4-8, 1983).
PUB TYPE Reports - Research/Technical (143) -- Speeches/Conference Papers (150)
EDRS PRICE MF01/PC01 Plus Postage.
DESCRIPTORS Clinical Diagnosis; *Developmental Stages; *Diagnostic Tests; *Disabilities; Early Childhood Education; *Handicap Identification; Infants; *Information Needs; *Parent Attitudes; Parent School Relationship; Young Children

ABSTRACT

Parents' views concerning the developmental assessment of their special children were evaluated, and a diagnostic model was developed based on the findings. Nineteen families whose 3- to 36-month-old children were undergoing first-time developmental evaluations were studied through questionnaire and interview responses. Twelve recurring themes mentioned by the parents fell in five areas: parents' desire for information, the relationship with the evaluator, parents' views of test validity, parents' need for hope or reassurance, and the desire to have both parents present. All families mentioned that they desired information from developmental evaluators. The second most frequently-mentioned theme concerned parents' desire for their children to do for the evaluator the things they did at home. If the evaluator did not get a good picture of the child, parents tended to doubt the test's validity. The third area of themes involved the relationship with the evaluator. The fourth frequently mentioned area covered the theme of parents' need for hope or reassurance about their children. The model for developmental assessments covered setting up a continuing relationship with parents, offering information to parents, and seeking information from parents. An appendix lists the following information: the kinds of information parents either received and found helpful or wanted to know, factors related to the child's performance, parents' views of test validity, and areas about which parents seek hope or reassurance concerning their children. (SEW)

* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *

ED232382

U.S. DEPARTMENT OF EDUCATION
NATIONAL INSTITUTE OF EDUCATION
EDUCATIONAL RESOURCES INFORMATION
CENTER (ERIC)

- ☒ This document has been reproduced as received from the person or organization originating it.
☐ Minor changes have been made to improve reproduction quality.

• Points of view or opinions stated in this document do not necessarily represent official NIE position or policy.

Impact of the Diagnostic Process on Parents

Janice L. Hanson

presented to

The Council for Exceptional Children

61st Annual Convention

April 6, 1983

Detroit, Michigan

contact:
Janice L. Hanson
1816 Rawlings Place
Crofton, Maryland 21114

"PERMISSION TO REPRODUCE THIS
MATERIAL HAS BEEN GRANTED BY

Janice L.
Hanson

TO THE EDUCATIONAL RESOURCES
INFORMATION CENTER (ERIC)."

EC152680

Impact of the Diagnostic Process on Parents

In recent years, special educators have experienced a growing awareness of the importance of parents in their children's education, particularly with very young children. Research shows that parent involvement forms one of the crucial components of success in early intervention programs (Interact, 1981). Furthermore, the involvement of parents in educational planning through the individual education plan process leads to a need for them to understand assessment procedures and results.

Assessments, particularly initial assessments, hold great potential for influencing parents' attitudes towards their children's programs. The evaluator has the opportunity to influence the parents' feelings about professionals who relate to their children, and to affect the clarity of parent's perspectives of their children's abilities and necessary programming. Factors such as the supportiveness of the evaluator, the types of information given, and the way the evaluator involves the parents in the assessment process may affect these parental attitudes and perspectives. Psychologists and special educators need to attend to the parents' experience in the assessment setting, and to how that experience may affect the parents' own needs, the parents' interaction with the child, and the parents' future involvement in the child's educational programs. As a preliminary approach to this problem, the research presented here addresses the question, what factors in

the developmental assessment process are important to parents?

Research Design

Perusal of the literature uncovered few studies investigating assessment from a parent's perspective, with the exception of some surveys involving parents of older children (Dembinski & Mauser, 1977; Gorham, DesJardins, Page, Pattis, & Scheiber, 1975). It therefore seemed necessary to pursue an open-ended research study designed to explore possibilities. I chose a nontraditional design, borrowing from ethnographic approaches (Spradley & McCurdy, 1972). I entered the assessment situation considering the parents as experts about their experience and needs, and sought ways for them to teach me. The research design looked intensively at a small number of families, and its open-ended features allowed for hypotheses to develop during the course of observations and interviews.

Subjects

The study involved natural parents of children coming for first-time developmental evaluations. The children were between 3 and 36 months of age, and the parents had no other children with identified disabilities. Nineteen families who met these criteria participated in the study, 15 with couples and four with single mothers. Of the 15 couples, in 13 of the couples, both

mother and father participated, and in two only the mother participated.

Agencies

Assessments took place through four different agencies: a regional center that coordinated services for children with developmental disabilities, a private therapy organization, a division of genetics in a hospital complex, and a followup clinic for high risk infants.

Research Process

The research process consisted of the following six steps:

1. Having the parents fill out a questionnaire before the assessment. The questionnaire gathered information about what the parents expected from the evaluation, their attitudes toward programming, and what they already knew about their children's functioning and programming needs.

2. Observing the evaluation, with the aim of getting as close as possible to the way the session would look to the parents. Data from the observation included detailed notes about the content of the session and a series of ratings.

3. Predicting possible parent responses to the evaluation.

4. Interviewing the parents, asking them to answer a number of open-ended questions and complete a form rating the different

aspects of the evaluation session in terms of importance to them.

5. Predicting possible long-term parent responses to the evaluation.

6. Interviewing the parents again four months after the evaluation, asking the parents to answer a number of open-ended questions. The followup interview was designed to look for changes in parents' perspectives on the evaluation, their retention of information given to them, and their followthrough on recommendations from the evaluation.

Data

The data used to acquire the information presented here included transcripts of all interviews conducted with the parents. The interviews were guided by sets of questions, but proceeded flexibly, with different questions arising within each interview.

Analysis

After taping and transcribing the interviews, analysis involved working carefully through each transcript to look for themes and insights. A list of common parent reactions gradually evolved, with specified themes and related points. The next step of analysis involved re-reading each interview, coding comments

according to the numbers of the themes and related points. After tallying the coded comments, all themes mentioned by more than half of the families were included in the results.

Results

The results included 12 recurring themes (see Table 1) which fell in five areas: parents' desire for information, the relationship with the evaluator, parents' views of test validity, parent's need for hope or reassurance, and the desire to have both parents present.

By far the most frequent theme, mentioned in some way by all families, was that parents desire informations from developmental evaluators. Table 2 shows the kinds of information parents either received and found helpful, or mentioned that they wished they had received. Some parents noted that they retained information about suggestions for working with the child best if they saw demonstrations along with explanations. While desiring information, however, a number of parents did not know what questions to ask, and a few felt unsure of whether the tester wanted them to ask questions.

Perhaps the desire for information appeared universally because of parents' expressed need to do something to help their children, and to feel like they had done everything possible. Twelve families of children with developmental needs mentioned this need.

Two other themes related to information included parents' expecting a competent professional as an evaluator, and their desire to receive some results the day of the testing. Parents of children with developmental problems find it hard to deal with uncertainties about their children's futures (mentioned as a separate theme by seven families), and perhaps this heightens their appreciation for some immediate feedback. Some idea of how the child did on the test, along with a few immediate suggestions of things to do, seems to meet this need to know some results, and parents generally understand that an evaluator may need time to consider the child's responses more carefully before presenting details. When she did not get any results the same day, one mother said she found it especially hard to wait beyond the time the evaluator had promised the results.

The second oft-mentioned area of themes concerned parents' desire for their children to do for the evaluator the things they did at home. Eighteen of the 19 families mentioned some factor related to this. If the children did perform well, or if the evaluator incorporated enough information from the parents about the children at home, parents tended to see the test as valid. If the evaluator did not get a good picture of the child, parents tended to doubt the tests's validity. Table 3 shows factors related to the child's performance and the accuracy of the picture of abilities provided by the assessment. An additional theme related to this and mentioned by 10 families was that parents did not mind answering questions, even a lot of

questions, if they saw the questions as relevant, particularly if the questions helped the tester get a better picture of the child.

The third area of themes involved the relationship with the evaluator. The developmental tests seemed to work best in the context of a continuing relationship with the evaluator (mentioned by 13 families). Related points included the following:

1. Not knowing what to expect from the evaluation increased anxiety for many parents, and prior phone or other contacts would help a parent feel more comfortable at the evaluation.
2. Prior contact between the evaluator and the child helps the child feel more comfortable.
3. Subsequent contacts helped in retaining information, solving problems, and acquiring more information.
4. Subsequent contacts by the evaluator established a feeling of caring.
5. Previous or subsequent contacts enable the evaluator to see more of what the child can do.
6. Parents appreciate knowing they can call back if they need to.
7. Some parents thought it easier to relate to only one to two professionals at once.

Within the relationship with the tester, most parents (16 families) mentioned the evaluator's warmth as a factor in making them feel more comfortable. They noticed professionals who

showed concern for them as parents or seemed to know what they go through. Twelve families mentioned special appreciation for professionals who seemed willing to spend needed time talking or who in some fashion went out of their ways for the parents, or expressed frustration with a professional who seemed unwilling to spend needed time. Twelve families also mentioned the importance of an evaluator relating with sensitivity to the child, showing that s/he likes the child by smiling, holding, playing with, or commenting about the child, and treating the child normally.

The fourth frequently mentioned area covered the theme of parents' need for hope or reassurance about their children. Parents of handicapped children sought hope for their children in ways an evaluator can usually provide realistically. Even parents of high risk children who did well developmentally often sought reassurance about their children's progress. Table 4 lists sources of hope and reassurance that parents found helpful.

The final theme mentioned by more than half of the families was that they would like both parents involved in evaluations, especially to hear results. Eleven of the 15 two-parent families agreed that they thought this important. Four mothers wanted the father present when he did not especially see the need to attend, but most fathers wished for an opportunity for involvement in the evaluation.

Implications for a Diagnostic Model

The themes and comments which emerged while listening to these families lead to a model for developmental assessments which includes setting up a continuing relationship with parents, offering information to parents, and seeking information from parents.

Setting up a continuing relationship may involved simply phone contacts before and after the evaluation. A phone contact before the evaluation affords an opportunity to explain what to expect from the evaluation and thereby alleviate some anxiety. It also provides a chance to involve the parents in decisions that will help make the evaluation a more satisfying experience for them--decisions about the time of day and place the child will perform best, and whether the evaluation can be scheduled at time when both parents can attend. If the evaluation forms part of a developmental intervention program, the tester may want to offer a visit to the program for the parent and child sometime before the test, so they will feel more comfortable at the evaluation. During the evaluation, the relationship can be enhanced by seeking out the parents's concerns, trying to spend time as needed, and responding with caring comments and actions for the child. After the evaluation, if continued contacts will not occur as part of a program, parents appreciate mention of the evaluator's availability for phone calls if needed.

Specific mention of an opportunity to ask questions forms

the first step in offering information parents. Suggesting before the evaluation that they think about their questions and bring them to the assessment may help them formulate questions, and asking at the evaluation whether they have questions will clarify that questions are welcome. Having parents present during testing provides an opportunity to share information for which they may not know how to formulate questions. A continuing dialog during test administration about what you look for and what responses you see from the child helps parents understand the test, the meaning of the child's performance, and the resulting developmental ages and recommendations. Some immediate information on results and some recommendations with demonstrations satisfy the immediate need for information on developmental status and helpful intervention.

Finally, seeking information from parents helps them feel involved in the process and contribute to the picture of their child's developmental abilities. Parents can tell how the child's performance during the test compares with the things they have seen at home, they can describe behaviors not tapped by the test, and the often can suggest something to help their child perform better during the test.

Conclusion

This research report describes a process of attempting to understand parents' experiences and needs during developmental

evaluations of their young children. In addition to the specific suggestions which emerge for interactions with parents, the continual attempt to see situations from the parents' points of view establishes an ongoing process of learning. This process leads to continual awareness of new ideas and to tremendous respect for the strength, compassion, and insight possessed by the parents of young children with developmental needs.

References

- Dembinski, R. J., & Mauser, A. J. What parents of the learning disabled really want from professionals. Journal of Learning Disabilities, 1977, 10(9), 578-584.
- Early intervention for children with special needs and their families. Chicago, Illinois: Interact, 1981.
- Gorham, K. A., DesJardins, R. P., Pattis, E., & Scheiber, B. Effect on parents. In N. Hobbs (Ed.), Issues in the classification of children (Vol. 2). San Francisco: Jossey Bass, 1975.
- Spradley, J. P., & McCurdy, D. W. The cultural experience--Ethnography in complex society. Chicago: Science Research Associates, 1972.

Table 1
Recurring Themes

<u>Frequency</u>	<u>Theme</u>
19	Parents want information from developmental evaluators
18	Parents want their children to do for the evaluator what they do at home. If they do, it helps parents to see the test as valid. If not, they are bothered, and may see the test as invalid.
16	Evaluator warmth helps establish a comfortable atmosphere for questions and comments. Parents appreciate professionals who show interest and concern for them as parents as well as for their children, or who seem to know what they go through as parents.
14	Parents seek hope or reassurance about their children
13	An evaluation works best in the context of a continuing relationship, with some contacts between parents and evaluator before and after the test session.
12	Parents of delayed children feel a need to do something to help their children, and need to feel they have done everything possible.
12	Parents appreciate professionals who seem willing to spend time with or for them, or feel frustrated after interactions with professionals who seem unwilling to spend needed time.
12	Parents especially appreciate an evaluator who is sensitive to their child.
11	Two-parent families generally want the father involved in evaluations, especially to hear results.
10	Parents do not mind answering a lot of questions if they see the questions as

relevant. They may even view questions as helpful, because they provide a chance to add information about things the evaluator missed while watching the child.

- 10 The day of testing, parents like some information about how the child did.
- 10 Parents look for an evaluator who is professional and competent.

Table 2

Information Desired by Parents

<u>Frequency</u>	<u>Item</u>
15	Suggestions about what to do if the child has problems.
14	Age level information about the child's development.
13	Articles or books related to their child's development, diagnosis, or needs.
12	In general, want more information than they have gotten, or what to learn as much as they can.
10	What programs are available for the child.
10	In general, how the child is doing, or what the child is doing.
9	The meaning of test items.
9	Honest presentation of what the professionals know about the child.
7	The expected performance for the child's age.
7	A written report about the evaluation.
5	Easily understood explanations.
4	What to expect from future programs.
4	Prognosis
3	Information about the child's diagnosed condition.
3	Explanations about what the child is and is not doing on test items.
2	What the child does well.

- 1 Specific instructions on how to contact programs.
- 1 The meaning of age-level scores.
- 1 Verbal explanations to accompany written information.

Table 3
Factors Affecting Children's Performance and
Parents' Views of Test Validity

<u>Frequency</u>	<u>Item</u>
11	Parents want the test in a place where the child can be comfortable. Some children do things at home that they do not do other places. Some children perform fine in other places.
8	There is not enough time in one visit to see all that the child can do.
6	The evaluator can get a good picture of the child through thorough questions asked of the parent, or a parent sharing information about the child.
6	A child does not perform well when tired, hot, sick, or otherwise uncomfortable.
5	The child does better with a parent present.
5	Parents want thorough testing.
3	The evaluator's way with children helps the child to do well.
2	Some unstructured time to watch the child play would broaden what the evaluator sees.
2	The parent can give ideas of how the child might do better in the situations.
2	Some children do not do well with unfamiliar people.
1	It helps if the evaluator persists to get the child to perform.
1	The evaluator needs to give the child time to accomplish the tasks.

- 1 Too much delay between the test and the sharing of results makes the test results too different from the child's current abilities.

Table 4
Sources of Hope and Reassurance

Parents seek hope or reassurance about their children in:

Frequency

- | | |
|----|--|
| 12 | a. encouraging signs in the child's development. |
| 7 | b. encouraging comments from an evaluator about the child--comments about something the child does well, or reassurance that the child will make progress. |
| 6 | c. knowing help (services, programs, medical intervention) is available. |
| 6 | d. good health, pleasing temperament, attractive appearance, or other positive characteristics of the child. |
| 4 | e. reassuring information about the child's developmental status. |
| 3 | f. finding out about other handicapped children or children similar to their own who have improved or done well. |
| 3 | g. comments that the child does well in relation to other children with the same diagnosis, e.g. Down's Syndrome. |
| 1 | h. re-evaluation which might show progress. |